



25 MILLION RARE DISEASE PATIENTS DESERVE BETTER

Pelosi – Wyden “Deal” to Impose Price Controls, Harm Rare Innovation

Washington, D.C. (11-2-2021) - While negotiations continue regarding the components of the "Build Back Better" plan, recently released information regarding prescription drug pricing, and closing the catastrophic coverage in Medicare Part D continues to offer a “half a loaf” to rare disease patients who depend on not just access in the program, but also in encouraging a robust pipeline to continue providing hope of new therapies.

The time has come to close Medicare Part D out of pocket costs. However, RAAP continues to have concerns with the proposed framework by Speaker Pelosi and Chairman Wyden.

Recently, RAAP released a study looking at current Medicare proposals that illustrated the significant impact of redesign. However in 2020, when RAAP explored expanding rare disease company contributions in a redesign proposal similar to the Pelosi-Wyden, we found that costs would increase for rare companies between 400 and 800 percent. This is before understanding the impact of other cost control provisions in the current proposal.

Michael Eging, Executive Director of RAAP noted, “Throughout the course of this debate, RAAP has continuously communicated with Congress on the very real consequences to rare disease patients through redesign and increased price controls. The fragile rare disease marketplace represents hope to millions of Americans who experience a rare disease. Increasing costs between 400 to 800 percent on rare medicines just in redesign will reduce incentives to invest in rare diseases, cripple emerging rare companies with limited resources to make-up the loss in revenue and reduce the pipeline for new therapies.”

RAAP urges Congress to rethink such proposals that couple cost increases for emerging and rare companies with additional price controls. For this reason, RAAP continues to support efforts such as the bi-partisan Menendez-Cassidy bill which would close out of pocket costs, and modernize the benefit design.

For interviews, e-mail media@rareaccessactionproject.com

###

RAAP, [the Rare Access Action Project](https://rareaccessactionproject.org), is a non-profit founded by a coalition of emerging and pre-commercial rare disease companies and patient organizations working together to develop solutions to access challenges with Rare Disease therapies and care. Find us at <https://rareaccessactionproject.org>